

The Michigan FAS Web



*"When spider webs unite they can tie up a lion."
~African Proverb~*

Former Grand Rapids Volunteer Now Working on FAS in our Nation's Capital

Katie Moody had no idea that a simple class assignment during her junior year at Grand Valley State University (GVSU) would end up taking over her life...

I first became involved in the world of FAS when I began classes in the Public and Nonprofit Administration program at GVSU. Projects in two classes required involvement in a condition-specific public health initiative. Finding myself interested in the substance abuse arena, I attended a meeting for a new initiative focusing on preventing the affects of substance abuse on women and children. It was at these meetings where I met Sarah Horton Bobo.

Sarah and I shared an equal excitement for the issue and enjoyed bouncing ideas off of each other. I liked feeling involved in a real-world issue instead of a classroom case study. Recognizing my enthusiasm and energy, Sarah invited me to attend a meeting of the Kent County Fetal Alcohol Syndrome Advisory Committee which she coordinates from the Kent County Health Department. I became a regular participant at Advisory Committee meetings.

When it came time for me to choose an internship, selecting the organization was not a problem. The more I worked with parents and professionals in the field of FAS, the more I wanted to stay involved. I was already familiar with the people and activities of the Advisory Committee, and the idea for a Mother's Day Community Awareness Campaign that I had casually suggested was getting discussed at the table. Working with the group was a win—win situation. As an intern, I was able to put the time and effort into FAS activities without wor-

rying about taking time away from schoolwork and the Advisory Committee was able to conduct an innovative awareness campaign.

After graduating from GVSU, I traveled to Washington, DC for a one week master's class and fell in love with the city. When I returned home and told my associates at the Advisory Committee that I would be leaving, we all hoped I would be able to continue making a difference in the field of FAS. Sarah put me in contact with Kathy Mitchell, national spokesperson for the National Organization on Fetal Alcohol Syndrome (NOFAS).

Since I was moving to DC without a job, I went ahead and let Kathy know I would be in the area and was interested in helping out at NOFAS, either as a volunteer or employee. Shortly after my move, I was brought on as a part-time employee at NOFAS. The staff was very pleased with my previous experience with the issue.

It is really exciting working for the National Organization. I am meeting and contacting people who were previously just names on journal articles. My responsibilities include revising our website, re-introducing our newsletter, Native American programs, national relations, intern recruitment, and future programs. I definitely miss working closely with the parents, the kids, and other caring community members. Much of our business is done in a



Success for Students with FASD

My name is Heather Gauck. I am a special education teacher in Grand Rapids, Michigan. At the age of twelve I had the experience of being part of a family who took in 2 foster children who had Fetal Alcohol Syndrome. Seventeen years later they are both my adopted brothers and I have them to thank for leading me to my career today. It was this hands on experience that taught me what it is really like to have this syndrome. I was fortunate to have parents who put their whole hearts and minds into making life as fulfilling for my brothers and making sure they received everything they needed in terms of services. It was this early intervention that changed the outlook for both of the boys. It has been a long tiring road filled with ups and downs but they are now both high "B" average students and one even made it to the National Honors Society last year. My message is one of hope!

This past November 21st and 22nd, I attended the Fetal Alcohol Syndrome Summit 2002 in Anchorage, Alaska. There was an incredible turn out of 613 attendees. Dr. Ed Riley was the keynote speaker and gave a talk on FASD and brain imagery. The main idea emphasized during the talk was that research of the brain is showing that individuals who do not have the facial features of FAS can have damage in the same areas of the brain as those individuals who do exhibit the facial features. These are the students that have always been my main concern as a teacher—the ones who do not look disabled but have brain damage nonetheless.

At the Summit, I was also able to listen to two incredible speakers who spoke about strategies that teachers can use in the classrooms. The first speaker was Julie Gelo. Julie is a Family Advocate from the Washington State FAS Diagnostic and Prevention Network. More classroom strategies were provided by Paula Cook who is a teacher with Winnipeg Schools in Manitoba, Canada. Here are some of the highlights from those workshops:

Gems from Julie:

- Ask to have students suspected of having FASD assessed with the Vineland Adaptive Behavior Scale. This tests provides very valuable information about student performance.
- Use assigned seats on the bus and invite the bus driver, playground supervisor, etc. to the student's Individualized Education Program (IEP).
- Create a plan for times when a substitute teacher is at school and have the plan written into the IEP. The plan might involve finding one agreeable adult in the school (such as the librarian or custodian) to provide an alternative setting if the child cannot handle his or her behavior with the substitute teacher. It may be that no "book" learning happens but it should result in the student not being suspended and having their self-esteem intact at the end of the day.
- Write homework limits into the IEP. For example, set a maximum of 20 minutes for reading and 20 minutes of additional homework. When time is up, if the child has been working hard, the parents will draw a line and sign the homework to show how much the student accomplished.

Pearls from Paula:

- ♦ Teachers should use less words and wait longer for students' responses. As teachers we tend to give directions and if there is no immediate response we re-explain a different way and we even sometimes step closer to the student. This can all be confusing and over-stimulating for students with FASD.
- ♦ Use as many sensory integration tools as possible.

(Continued on page 3)

"With the correct diagnosis, early interventions and continuation of services individuals who have this syndrome can have a positive future!"

(Continued from page 2)

- ble. (Seat cushions; gum, hard candy, and/or pretzels; multi sensory strip attached to desk; head phones to block out noise; a clip board to do work on the floor or in a small space; allow drawing, doodling, or mazes during lectures.)
- ♦ To prevent problems in line, ask the student to run around the playground to check for items left behind or send them to the classroom door to count balls that have been returned to class. For older students have them bring something to the next class for you.
- ♦ Allow baseball hats to be worn to cut down glare. Caps can also help a child ignore another student if they are worn tilted over the face.
- ♦ Tape vocabulary words, math facts, etc. on bean bags and throw them down stairs or down the hallway. Have the student run after them, bring them back and read what is on them.

- ♦ The KEY is to be 90% proactive and 10% reactive—Plan for Everything, Prevent Everything!

I have been trying many of these strategies in my classroom and I have been happy to see some positive responses. Even after living in the same house as two individuals with FAS and being very familiar with the syndrome, at times I forget to use the skills I have learned when teaching. I will not say that once you learn these strategies it becomes easy to teach students with FASD. It is a challenging and stressful job. However, what keeps me going is to know that even by implementing some of these strategies, these students are making progress and having positive experiences. My brothers were lucky to have an optimal setting for their childhood, however, I was even luckier to have them as my brothers. They taught me first hand what it means to live with the daily struggles and triumphs of having FASD. My dream is to see other individuals who have FASD overcome the impossible as my brothers have.

Lenawee County FAS Community Project

The Lenawee County FAS/E Advisory Committee is very active. So far this year the members of the committee have spoken to 15 different audiences about preventing FAS/E and recognizing FAS/E in those we serve. Our efforts appear to be paying off. When we approach businesses about posting warnings they already understand the importance of our message.

This year we discovered a new way to spread our prevention message. Middle school and high school students in our area love to pass notes on "Post-its". We had our symbol "ghosted" on neon post it notes and are handing out Post it note pad to students every chance we get. Every time a student writes a note and passes it on, our message, "Alcohol and Pregnancy Don't Mix", is being passed on as well.

Our parenting support group is small but strong. This year each parent received a book "All I Can Be: living with Fetal Alcohol Syndrome or Effects" by Liz and Jodee Kulp. This is the most practical book I have found. One teen sat down and started reading the book right at the Christmas party. She said "This is my life." The book has been such a hit that we will put in a second order. If you would like to check it out visit www.betterendings.org. Our parents say you'll find it very helpful.

For more information, contact Jackie Johnson at jjohnson@lcmha.org or (517) 265-6976

Former Grand Rapids Volunteer cont...

(Continued from page 1)

broader scope and requires a lot of time in the office, and we miss out on the personal contacts. However, we get daily phone calls from individuals who have either just received a diagnosis themselves or have a spouse, child, or friend who has. Other callers include women who suspect they may be pregnant and have recently had a binge episode, media seeking scientifically and politically correct quotes, and other organizations who want to use our materials.

The greatest difficulty is the hard truth of being a small nonprofit. We may be national, but we are unable to be nationwide. Bureaucracy and finances get in the way of so many things we want to do. Working for such an under recognized issue makes it an even tougher battle. I am thankful for all of the other groups working in communities

throughout the nation, such as the one I started with, who make a difference on the local level. Most recently, a few of “my moms” from Grand Rapids, Patty Brewer and Cathy Meyers, have agreed to help NOFAS educate medical students by presenting to two classes at Northwestern University as part of NOFAS curriculum there.

Hopefully, our continuous efforts at increasing public awareness will be successful. We know things can only get better especially when we consider the great need, such as the documentation from the University of Michigan’s latest research showing 15% of pregnant women are still drinking alcohol. Together, we can decrease that number.

Katie Moody can be contacted via email at katiem@nofas.org or 202.785.4585.

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Grand Rapids, MI 49503